

### Participating in a Clinical Trial

# So You Want to Participate in a **Clinical Trial?**

Here's what you need to know before deciding to take part



Clinical trials come in all shapes and sizes.

They are designed to:

compare existing treatments

prevent disease

## **But First: Some Rules**

Rules protect the rights, safety and well-being of anyone who takes part in a clinical trial. Those same rules also ensure that the trials are conducted according to strict scientific and ethical principles.

However, US rules or regulations may not exist or be enforced in other countries. Going overseas for a clinical trial, known as "Stem Cell Tourism," can be dangerous—or even life-threatening.

## The best way to protect yourself is to be informed and ask your doctor the right questions:

What is the purpose?

How will I be told my results?

What costs will my insurance cover?

Will I have to pay?

How long do I have to make up my mind'

How long will it last?

What are possible side effects?

What happens if I leave the trial?

What does it involve?

Can I speak to past participants?

What are potential benefits?

Will my daily life be affected?

How long until I get results?

Who is in charge of my care?

How will my information be kept private?

Will I have post-trial check-ups?

Feeling overwhelmed? Here's some helpful tips to help you make an informed decision:

Don't go it alone—talk to a family member or friend for support or help



Be prepared—plan your questions ahead of time



Leave nothing to chance—write down all answers, or consider bringing a tape recorder



"But how do I find the right trial?"



Your #1 resource for US-based trials

Maintained by National Library of Medicine
Gives public easy access to publicly and privately supported clinical trials
Lists which patients are eligible for which trial

# Above all else: have realistic expectations

Taking part in a trial does not mean you will benefit from it.

Early-stage trials are usually just to test that the method is safe. Even later-stage trials may not have benefits for everyone and benefits will vary from person to person.

But the lessons learned from even the smallest trial may prove invaluable in the long run—in helping us better understand the science

Want to learn more? We've got you covered. Here are some of the best and most up-to-date resources to guide you and help you make the best decision for your health or the health of a loved one:

Clinical Trials, What Patients and Healthy Volunteers Need to Know, by Dr. Lorna Spied (Oxford Univ. Press)

http://acloserlookatstemcells.org (source: International Society for Stem Cell Research)
http://www.cancer.gov/cancertopics/factsheet/clinicaltrials/clinical-trials (source: National Cancer Institute)

http://www.clinicaltrials.com/study\_participants/questions\_to\_ask.htm (source:Clinicaltrials.gov)

### Find Out More:

CIRM-Funded Clinical Trials Where CIRM Funding Goes Stem Cell FAQs

If you or a family member is interested in participating in a clinical trial, please visit clinicaltrials.gov to find a trial near you.

 $\textbf{Source URL:} \ http://www.cirm.ca.gov/patients/patients-toolbox/participating-clinical-trial$